

AN EXAMINATION OF DIFFERENCES BETWEEN MUSIC THERAPY AND TALK  
THERAPY ON INTIMACY IN A FAMILY-PATIENT RELATIONSHIP  
AT THE END-OF-LIFE

By

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## Abstract

The purpose of the study was to examine differences between music therapy and talk therapy on intimacy in a family-patient relationship at the end-of-life. To determine differences between music therapy and talk therapy, the researcher measured frequency of ten hospice family caregivers' intimacy acts, as indicated by (a) verbal intimacy, (b) affective intimacy, and (c) physical intimacy. Results showed no significant differences in verbal intimacy actions of family caregivers towards a dying loved one when comparing music therapy with talk therapy. Significant differences were found in affective intimacy and physical intimacy between the treatments. Music therapy resulted in significantly higher affective intimacy, and physical intimacy measures, when compared to talk therapy. Music therapy may be an effective therapeutic modality for family caregivers of dying patients to increase emotional and physical intimacy in a family-patient relationship at the end-of-life.

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## **Chapter 1**

### **Introduction**

Family caregivers express various emotions when placing their loved one in hospice including a sense of helplessness, guilt, sadness, anger, and anxiety due to separation, death or the hereafter. Many suffer significant losses, including the end of meaningful interactions and emotional intimacy when their dying loved one can no longer speak, hold their hands, or respond with a blinking of the eyes, or moving of the head. During such difficult situations, family caregivers may suffer from depression, anxiety, or post-traumatic stress disorder (PTSD), causing drastic changes in the role and relationship with their loved one (Worden, 2003).

In consideration of the various roles facilitated by family caregivers during hospice care, the family is a recipient of hospice care. Hospice services are available to meet ongoing needs of the family while the patient is dying and during bereavement after the death of a loved one. The philosophy of hospice involves both patients and family members as the unit of care with its specific emphasis on holistic care (National Hospice and Palliative Care Organization, [NHPCO], 2007). Viewing one's life-limiting illness might appear a solitary experience in that only one is terminally ill, but relational aspects of patients' experiences become an important component in pursuit of appropriate care. At times, one's life-limiting illness can have a deleterious effect on family relationships and communication (Gates, 2001).

To facilitate the potentially difficult process of death, music therapy functions as an effective emotional support mechanism for family caregivers to engage in patients' end-of-life process (Hilliard, 2005b). Many research studies documented the effectiveness of music therapy in supporting family needs in hospice care. (Heath & Lings, 2012; Krout, 2003; Lindenfelser, Hense, & McFerran, 2011; Magill 2009a; 2009b; McFerran, Roberts & O'Glady, 2010;

Schwantes, Wigram, McKinney, Lipscomb, & Richards, 2011). Music therapy literature supports the use of music therapy to open channels for intimate communication through which family members can gain increased understanding of the meaningful value of the relationship with their loved one (Brotons & Marti, 2003, Heath & Lings, 2012; McFerran, Roberts & O'Glady, 2010). Furthermore, music therapy plays a unique role in family support by transitioning from passive acceptance of death and dying to active engagement in meaningful moments with a dying loved one (Krout, 2003).

An emerging body of evidence supports the use of music therapy interventions for family caregivers. However, music therapists often report information qualitatively; therefore empirical evidence in this area is limited (Hilliard, 2005a). Although the qualitative studies are valuable in illustrating the details about using music therapy for terminally ill patients and families, most of the sample sizes in the existing literature are small, which limits generalization of the results to the hospice population (Bosanquet & Salisbury, 1999; Hilliard, 2005a). Hilliard (2005a) recommended that researchers conduct empirical studies to provide a generalization of results in the field of hospice music therapy. Thus, there is an increased need for empirical studies to support the benefits of music therapy in hospice settings.

As family members experience high levels of emotional distress due to the impending separation from their loved one, they must develop positive coping strategies, such as the use of music therapy interventions to process their grief and bereavement (Magill, 2009a). In order to provide effective treatment modalities, this current research study aims for empirical evidence in understanding if music therapy makes a difference to facilitate meaningful relationships between family caregivers and dying patients, in comparison to talk therapy. Therefore, the purpose of this study was to examine the differences between music therapy and talk therapy on intimacy in

a family-patient relationship at the end-of-life. The research question asked: Was there a difference in frequency of family caregivers' intimacy acts, defined and recorded by verbal intimacy, affective intimacy, and physical intimacy with their dying loved one when comparing music therapy and talk therapy?

## **Chapter 2**

### **Review of Literature**

Family caregivers of hospice patients have a high risk for emotional and relational distress, due to drastic changes in patients' appearance, behaviors, and symptoms. Caregivers find it difficult to feel close to and communicate with their dying loved one who is minimally responsive, and therefore unable to speak, nor able to make wishes known. The current review begins with defining the philosophy of hospice care, the role of family caregivers in hospice, and theories of intimacy. Without intervention, family caregivers may continue to experience high levels of stress when providing care for patients approaching death, which can impact quality of life in patients and families. Coping skills are essential to remain effective in a caregiving role, and prepare for death and dying of a loved one. Thus, the second half of the review focuses on coping strategies, specifically emphasizing talk therapy and music therapy that are aimed at improving a family-patient relationship at the end-of-life. Finally, this chapter will conclude with the purpose statement of this study and the research questions being addressed.

#### **Philosophy of Hospice**

Hospice is not solely a place where people go to spend their last days, but rather a philosophy of care that focuses on quality of life and comfort for patients facing a terminal illness and their family. This hospice philosophy of care first emerged in England through the work of Cicely Saunders (1967) who was a medical doctor, a nurse and a social worker. Using her experiences across various healthcare disciplines, she became aware of the increased psychosocial and spiritual needs of dying patients, who often felt isolated and alone. She created the idea of *total pain* for the terminally ill to identify and relieve all levels of suffering including physical, emotional and spiritual.

While Saunders established the first modern hospice movement, Dr. Elizabeth Kubler-Ross (1969) developed the basic tenets of hospice philosophy, providing a theoretical framework of psychological stages of dying. Kubler-Ross made a plea for ‘home care’ as opposed to institutional or hospice settings, and argued that patients and their families have a choice in this decision about their care – whether to be at home or in other places. Both Saunders and Kubler-Ross views shaped the philosophy of modern hospice to integrate physical, psychological, emotional, and spiritual aspects of care, helping patients and families come to terms with their own deaths, and the deaths of their loved ones.

The modern hospice movement provided much support to develop a definition of hospice and palliative care. According to the NHPCO (2015), hospice care relies on “the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.” Additionally, hospice care as noted by the National Quality Forum (2006) is “a service delivery system that provides palliative care for patients who have a limited life expectancy and require comprehensive biomedical, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition. It also supports family members coping with the complex consequences of illness, disability, and aging as death nears” (p. vi). Both definitions of hospice and palliative care specifically include family members as the unit of care, requiring the care plan that is directed at both patient and “family members who provide support and with whom the patient has a significant relationship” (National Consensus Project for Quality Palliative Care, 2013, p. 9). Philosophical views and approaches towards hospice care may vary among professionals, but all definitions have common themes of optimizing quality of life in patients and family members, and accepting death as the inevitable end.

With greater recognition of the importance of quality of life during life-threatening illnesses, the primary goal of hospice care places special emphasis on symptom control and on dying as a process. Death should not be hastened over prolonged periods of time in hospice care, and there is an effort to affirm and improve quality of life until a natural death occurs (NHPCO, 2010). This process of affirming life embraces a holistic phenomenon that transcends multidimensional quality of life. This holistic approach to hospice care has important implications for hospice professionals to treat patients as a whole person, not as a disease.

Specifically, the Last Acts Task Force on Palliative Care (1998) documented the primary goal of hospice and palliative care “to achieve the best quality of life by meeting the physical, psychological, social, spiritual, and existential expectations and needs of patients while remaining sensitive to personal, cultural, and religious beliefs, values, and practices” (p.110). While curative models of medical care have put more emphasis on a reductionist approach by viewing the body as discrete components, hospice care maintains a holistic philosophy incorporating multidimensional needs of the patients and family (NHPCO, 2010).

### **The Role of Family Caregivers in Hospice Care**

Family caregivers play an integral role in the dying process, helping patients manage and cope with a terminal illness. Family caregivers as defined by Mitnick, Leffler, & Hood (2010) are “over the age of 18 and “include relatives, partners, friends, and neighbors who assist with activities of daily living and complex health care needs that were once the domain of trained hospital personnel” (p.255). Patients with a terminal illness rely on family caregivers assisting with activities of daily living, providing medications, preparing meals, managing finances, advocating for health, and providing emotional support (Margaret & Sternberg, 2012; Mitnick, Leffler, & Hood, 2010). Thus, family caregivers play many roles in caregiving – a hands on care

provider, surrogate decision-maker, friend, companion, and advocate (Family Caregiver Alliance, 2003). Caregivers' ability to provide care significantly affects patients' comfort level and quality of life.

Complex care that is physically, emotionally, socially, and spiritually demanding for hospice patients can result in the neglect of family caregivers' own needs. A large body of research substantiates the effects that a terminal illness has on family caregivers' emotional, physical, spiritual, and social needs (Northouse, Katapodi, Song, Zhang, & Mood, 2011). Previous research examined that caregivers of terminally ill patients reported negative impact on their health such as anxiety, burnout, depression, fatigue, fear, guilt, hopelessness, sleep disturbances, and social isolation (Bevans, & Sternberg, 2012). Patients and their family caregivers experience similar levels of depression after the diagnosis of a terminal illness, but caregivers were significantly more anxious than the patients as the dying process continued (Tokem, Ozcelik, & Cicik, 2011). While patients approach their own death, family members are dealing with anticipatory grief and ongoing emotional suffering that occurs before and even long after a loved one's death (Nabel, 2011).

In addition, changes in patients' condition create additional challenges in caregiving, and frequently result in a loss of intimacy in a family-patient relationship (Mitnick, Leffler, & Hood, 2010). Gates (2001) introduced the term, *altruistic care* as opposed to mutual care, in which family caregivers provide care to their dying loved one without receiving something in return. *Mutual care*, on the other hand, emphasizes an equal relationship where both parties in the relationship give and receive in return (Gates, 2001). Although caring for patients across different levels of care is one-sided and somewhat disconnected from reciprocity, family caregivers of dying patients show higher levels of exhaustion from altruistic care than other



caregivers (Gates 2001), and feelings of inadequacy and emotional detachment in a relationship with their dying loved one (Bevans, & Sternberg, 2012). Therefore, it may have a deleterious effect on emotional and relational aspects of caregiving for patients approaching death.

## **Intimacy**

This review of family roles in hospice care reveals that closer attention needs to be paid to a family-patient relationship at the end-of-life. The word, “intimacy” is often used to describe a close connection with another, resulting from a close relationship through knowledge and experience of the person. Many definitions of intimacy were found in the literature (Collins and Sroufe, 1999; Collins and Sroufe, 1999; Reis & Shaver, 1988). However, the present study focuses on family relationships including parents, spouses, children, and siblings, which were targeted for this study.

This study incorporated Tolstedt and Stokes (1983)’s theory of intimacy into defining and measuring types of intimacy. Tolstedt and Stokes proposed a three-dimensional model for intimacy: (a) verbal intimacy, (b) affective intimacy, and (c) physical intimacy. Firstly, verbal intimacy refers to the depth of self-disclosure. Self-disclosure is not simply providing information to another person, but willingly sharing personal and vulnerable aspects to be more intimate with partners (Hu, Wood, Smith, & Westbrook, 2004). Self-disclosure includes the verbal sharing of personal feelings, thoughts, and beliefs of one person toward another (Eryilmaz, & Atak, 2009). Secondly, affective intimacy involves sharing of emotions such as warmth, love, and feelings of acceptance and connection to another to encourage reconnection and building of relationships (Eryilmaz & Atak, 2009). Affective intimacy could include both verbal and nonverbal form of emotional expression, but the present study focused on nonverbal expression only (e.g. facial mannerisms, eye contact) to avoid duplicating data with verbal intimacy. Lastly,

physical intimacy is not limited to sexuality, but includes physical closeness inside a person's space such as holding hands, hugging, or kissing (Popoola, Adebawale, Akintomide, & Olatomide, 2012).

### **Coping Strategies**

Family caregivers in hospice care are somewhat detached and emotionally distant from patients, especially when they become unresponsive, or in a coma approaching death. With increasing demand with the aid of a family-patient relationship at the end-of-life, many studies examined coping strategies in reducing caregiving burdens and improving intimacy levels with a dying loved one (Li et al., 2014; Papastavrou, Charalambous, Tokem, Ozcelik, and Cicik, 2015; Tsangari, 2012; Wong, & Walhagen, 2014). Coping strategies are an important indicator for hospice clinicians to facilitate meaningful interactions between family caregivers and patients approaching death. Caregivers' abilities to cope with death and dying of a loved one need to be reinforced using appropriate strategies. Hospice professionals should provide appropriate treatments acknowledging signs of distress in family caregivers, and its impact on a relationship with dying patients (Mitnick, Leffler, & Hood, 2010). Hospice professionals can positively affect the caregiving experience by addressing caregivers' emotional and relational needs, and facilitating intimate connections with patients approaching death. Therefore, clinicians' understanding of a family-patient relationship in end-of-life, and ability to provide coping strategies may impact quality of life in family caregivers and patients at the end-of-life. Among various disciplines in hospice care, the present study focuses on talk therapy and music therapy with an interest in their roles of family support.

## **Talk Therapy: Chaplaincy**

Talk therapy, as noted by National Institute of Mental Health (2016), is a range of treatments that involve counseling techniques to help individuals deal with stress, and unhealthy thoughts and behaviors. Hospice clinicians who are trained in providing talk therapy include a chaplain, social worker and grief and bereavement counselor (NHPCO, 2010). Chaplaincy has been a significant part of providing support in hospice and palliative care (Lloyd-Williams, Wright, Cobb, and Shiels, 2004; McCord et al., 2004; Piderman et al., 2008; Wall, Engelberg, Gries, Glavan, & Curtis, 2007).

Although one may think hospice chaplains only focus on pastoral care and religious needs of patients and family caregivers, chaplains offer a variety of counseling interventions, including life completion discussion, life review process, exploration of beliefs about death and dying, and relationship completion between patients and families (Esperandio, 2015). A fundamental aspect of chaplaincy in hospice care incorporates ‘spiritual aspects’ into chaplaincy services to provide counseling for those confronted complex problems imposed by a life-threatening illness (Lloyd-Williams, Wright, Cobb, and Shiels, 2004).

Many studies examined the role of chaplains in health care settings (Lloyd-Williams, Wright, Cobb, and Shiels, 2004; Puchalski et al., 2009; Galek, Handzo, Weaver, and Overvold (2006). Earlier literature tended to emphasize the religious roles of chaplains (e.g., prayer, religious services, spiritual practices and last rites performed by different religions), whereas recent studies focused more on the importance of spirituality, which does not necessarily include institutional religion, but involves the way individuals seek and find meaning and purpose of life (Puchalski et al., 2009).

Lloyd-Williams, Wright, Cobb, and Shiels (2004) surveyed 115 chaplains working within hospices to identify the role of chaplains in hospice care. Results indicated that their role generally involved spiritual and emotional support for patients and family caregivers. In addition, Flannelly, Galek, Handzo, Weaver, and Overvold (2006) surveyed 1,431 nursing, social work, medical and pastoral care directors to describe other professionals' perceptions of chaplains' role. There was substantial agreement across the disciplines as to the high importance of prayer, emotional support, and spiritual issues relating to grief and death. These findings reflect a recent increase in attention to the importance of chaplaincy at the end-of-life, in addition to a religious liaison role of the chaplain.

Although many studies did not involve family caregivers as primary data sources, patients' accounts of their relationship with family members were noted in the literature. In McCord et al. (2004) spirituality survey of 912 patients with a terminal illness, the patients reported that interest in discussions of spirituality was higher when anticipating the loss of their loved one. The experience of losing a loved one may be a time when spiritual needs previously unnoticed become apparent. Piderman et al. (2008) surveyed 535 medical surgical patients to identify reasons for wanting to see a chaplain. Patients valued the chaplains for providing comfort and support for their family and significant others. In Kernohan, Waldron, McAfee, Cochrane, and Hasson's study (2007), the main six spiritual areas described by patients were: to have the time to think, to have hope, to deal with unresolved issues in the past, to prepare for death, to express true feelings without being judged, and to speak of important relationships with family members.

In Johnson, et al.'s survey (2014) of 275 family caregivers of patients who died a year ago, half of the families spontaneously reported the value of a chaplain presence in fostering

meaningful communication with their dying loved one, indicating that family members use spirituality as a platform for coping with the guilt of letting go of a loved one. Thus, the chaplain role in death and dying should aim to meet not only patient needs, but also psychological and spiritual needs of family caregivers.

Chaplaincy has contributed to quality hospice services by providing a supportive environment in which patients and family caregivers can find meaning in death and dying. However, many research studies exclusively focused on self-report methods (e.g., survey questionnaires) as a way of gaining insight into the needs of family caregivers. Self-reports are useful sources of subjective information, but data may not be fully substantiated without observational evidence (Bruce & Desmond, 1997). Self-reported surveys should be compared to direct measurements such as observation, to evaluate the validity and reliability of outcome measures. By using direct measures for assessing family caregivers in observational and experimental studies, results may provide a comprehensive summary of the previous research and a comparison based on direct versus self-report measures in hospice populations.

### **Music Therapy in Hospice and Palliative Care**

Family-based music therapy is a growing practice in hospice and palliative care. Music therapy can be a therapeutic modality for family caregivers to express emotions and thoughts with patients who are actively dying (Savage & Taylor, 2013). Music therapy services provide a wide range of benefits to family caregivers such as opportunities for emotional expression and anticipatory grieving, and for the development of coping strategies to manage their grief and loss, improve communication, and find meaning in life and death. Existing research studies describe benefits of music therapy with an emphasis on family involvement in the dying process (Krout, 2003; Magill, 2009a; 2009b; Savage & Taylor, 2013).

Krout (2003) conducted case studies consisting of in-depth exploration of music therapy in five family caregivers of actively dying patients. The results showed that music therapy plays a unique role in family support by transitioning the family members from passive acceptance of the dying process to active engagement in interactive and meaningful moments with the patients. Specifically, five case examples of music therapy described family members holding vigil at a bedside. Krout documented how patients' symptoms or appearance may make it difficult for families to communicate with their dying loved one; music therapy sessions helped the families to reminisce, express themselves, say goodbye, and give permission to pass away. Krout highlighted the importance of family caregivers' presence to create more powerful and significant moments due to their shared values and experiences.

Magill (2009a; 2009b) performed two studies on the effects of music therapy on family caregivers. In her first qualitative study (2009a), seven family caregivers experienced music therapy services with their loved one diagnosed with cancer. In the music therapy sessions, the family caregivers appeared to gain increased perspectives of meaningful life experiences, and understanding of the personal value of the relationship with a dying loved one. The researcher found that use of music therapy opens channels for intimate communication and links thoughts to images and memories between patients and their family. This study concluded that the restoration of meaningful communication that family caregivers experience prior patients' death assists with relationship completion, preparation for death, and improved appreciation for the value of life.

In the second qualitative study by Magill (2009b), the researcher examined the spiritual meaning of music therapy for family caregivers using interviews. Caregivers reported feelings of joy in seeing the effects of music on their loved one, as well as enjoying music for themselves.

Another common feeling was a sense of empowerment that caregivers could respond and engage in therapy sessions with their dying loved one. This helped the caregivers face their impending loss by seeing the loved one in peace, and knowing they were somehow involved in that change.

Savage and Taylor (2013) also conducted a study of music therapy practice with family caregivers measuring their caring behaviors towards their dying patients. Forty family caregivers of the patients with terminal illness participated in this study. Using a Caring Behaviors Observation Sheet (CBOS), family members' caring behaviors were measured before and during music therapy sessions for 14 months. The most frequently observed caring behaviors of the family members during music therapy included: (a) increased eye focus on the patient, (b) softened facial expression, (c) emotional response of tears, and (d) moving a chair to sit closer to the patient. Results indicated that music therapy creates a safe environment in which family members focus more on their dying loved one even when non-responsive, and feel supported when acknowledging and expressing their feelings. Limitations of this study included the absence of a control group, and the lack of experimental investigation, yet the results of the study encouraged future research with a different study design, stronger measurement methods, and a larger sample.

Clair and Ebberts (1997) conducted an experimental study to examine the effects of music therapy on interactions between family caregivers and patients with late stage dementia. The researchers used an observational method to ascertain whether music helps family caregivers to initiate physical touch (e.g., kisses, hugs, arms around the shoulder) with a loved one suffering from severe dementia. Results revealed that physical touch was an important outcome during music therapy interventions in which family caregivers experienced physical and emotional closeness with a loved one at the last stage of dementia. Though Clair and Ebberts emphasized

the importance of music therapy to improve a family-patient interaction, there was no control group, and it was not clear if the improvement was due to the effect of the music therapy alone. Thus, the present study created a comparison group (i.e., talk therapy) to examine differences regarding physical touch compared to music therapy.

Qualitative studies made up the majority of research support in the area of music therapy practice with family caregivers of patients in hospice care; quantitative evidence is sparse. Hilliard (2005a) argued that quantitative data from large samples are needed to provide assurance of reliable and accurate data on the quality of music therapy services in hospice and palliative care. Due to the integrated role of family caregivers in the care of dying patients, family support is an important and vital component of quality end-of-life care. Although preliminary case studies and qualitative evidence support the outcomes, empirical research is necessary to examine how family caregivers receive or find coping strategies to enhance close connection with a dying loved one. Therefore, this study aims to gain an improved basis for understanding the difference between music therapy and talk therapy on a family-patient relationship in end-of-life.

### **Hospice Music Therapy in South Korea**

In South Korea, hospice music therapy has gained increasing attention despite its short history due to increased music therapy practicum and internship placements, and clinical employments in various settings (Jeong & Hwang, 2016). During the late 1990's, scholars who achieved a PhD degree in music therapy in the U.S. first introduced the term music therapy, promoted the idea that music therapy is comparable to other allied health professions, and contributed to the development of academic music therapy programs in colleges and universities in South Korea (Jeong & Hwang, 2016). However, more hospice music therapy research in



South Korea is needed. To date, only four research studies were found regarding the efficacy of hospice music therapy in South Korea (Lee & Choi, 2012; Choing & Choi, 2005; Jeong & Hwang, 2016; Kim & Kim, 2014).

Chong and Choi (2005) investigated the effects of music therapy on verbal and nonverbal expression for Korean patients in hospice care to decrease negative influences of isolation and self-concealment. Researchers described four patients' experiences of music therapy in hospice care, and measured patients' self-reported concealment levels through a pretest and posttest procedure using the Self-concealment Scale (Larson & Chastian, 1990). Results indicated that the use of music was effective in evoking emotional response related to life events and memories, with levels of self-concealment in every participant significantly decreased. The limitations of the pilot study included the small sample size, but the results encouraged future research with a larger number of subjects.

Lee and Choi (2012) studied the effects of self-selected music listening on pain relief and mood enhancement in Korean cancer patients. Twenty subjects received music therapy, and rated their perceived pain (Visual Analogue Scale) and mood (numerical rating scale for mood) before and after the therapy. There were significant differences in pre-test and post-test comparisons for the subjects as measured by self-reported mood and pain. The study again had a small sample size for statistical analysis, but the decrease in pain and mood disturbance in music therapy may suggest self-reported music listening as an appropriate intervention to improve mood and reduce pain in terminal cancer patients.

Kim and Kim (2014) conducted an experimental study to investigate the effects of music therapy on mood enhancement in terminal cancer patients in South Korea. Thirty-one patients received eight individual music therapy sessions for four weeks. Investigators obtained self-rated

emotional states of anxiety, depression, anger, and vitality before and after sessions. No significant difference was observed in anger. However, significant differences were found in anxiety, depression, and vitality. The data indicated that music therapy can be beneficial for positive mood changes in patients within the hospice treatment model.

Jeong and Hawng (2016) investigated Korean hospice professionals' perception regarding music therapy for the terminally ill, and what obstacles exist in utilizing music therapy in their agencies. Results indicated that 63% of 100 hospice professionals including a medical doctor and a nurse reported that they heard music therapy for the terminally ill. When asked if music therapy is necessary for hospice care, 89% responded "yes," but reasons for not being able to hire a music therapist were insufficient funds, and lack of understanding about hospice benefits among patients and families. The researchers concluded that there is a need to establish a financial reimbursement system for hospice care in order to fund music therapy programs. Furthermore, music therapy clinicians should become knowledgeable and comfortable providing education to patients and families regarding the clinical uses and benefits of music therapy in end-of-life care (Jeong & Hawng, 2016).

In a Kim (2010)'s survey on death and dying in South Korea, participants viewed death as a transition to another life, believing that the good and bad of what they have done to others will affect their future lives. Korean participants viewed a 'good death' would happen when one dies without pain at home surrounded by family members. The author concluded that it is critical to provide a supportive environment where patients and families can review a shared life to prepare for the next life after death. Although how patients and families spend last days together is an important part of a dying process in Korean culture, there is no music therapy study addressing a family-patient relationship at the end-of-life.

In addition, this review relating to hospice music therapy in South Korea revealed that all studies relied on self-report methods to investigate the effectiveness of music therapy. Self-report measures would be a valuable way to identify a subjective phenomenon, but use of observation tools may offer objective evidence of clinical outcomes over the course of therapy. By developing an observation tool for assessing a relationship between patients and families, this study can aid hospice professionals in developing effective treatments in hospice care.

### **Summary**

In hospice settings, family caregivers express a range of emotions as their loved one approaches death. Family caregivers suffer the loss of intimacy with their dying loved one who may no longer meaningfully communicate due to the body shutting down. Although the hospice philosophy views patient and family as the unit of care, an examination of a family-patient relationship that affects coping of family caregivers is warranted. During the last period of the patients' life, providing support for the development or continuation of an intimate relationship between family caregivers and dying patients becomes increasingly important. Therefore, the purpose of this study was to examine the differences between music therapy and talk therapy on intimacy in a family-patient relationship in end-of-life. The researcher compared the frequency of family caregivers' intimacy acts in music therapy and talk therapy sessions, as indicated by (a) verbal intimacy, (b) affective intimacy, and (c) physical intimacy. The research question asked: Was there a difference in frequency of family caregivers' intimacy acts, defined and recorded as verbal intimacy, affective intimacy, and physical intimacy with their dying loved one when comparing music therapy and talk therapy?

## **Chapter 3**

### **Method**

#### **Recruitment and Informed Consent**

The Institutional Review Board of the University of Kansas approved this study. In addition, as part of human subjects review process, a letter of agreement was obtained from a non-profit hospice agency in a midwest suburban area of South Korea from which potential participants were recruited. Interventionists (i.e., a chaplain and a music therapist) were the employees at the hospice agency, and invited patient-caregiver dyads to participate in this study. The interventionists then gave the researcher a list of potential participants who indicated interest in participating. The researcher visited them with the interventionists, and provided a written informed consent form translated into Korean before their participation in research.

Caregiver participants signed the informed consent document prior to participating in the study. Patient participants also signed the informed consent to participate in the research prior to treatments. For patients who were unable to make their own decisions and communicate their wishes due to loss of consciousness, coma, or impending death, primary caregivers with a Power Of Attorney (POA) for health care, or an identified surrogate decision maker provided signed informed consent. The primary family caregiver was the target participant for the study. Other family members or visitors who were present with patients were informed about the study procedure, but the researcher did not collect data from them.

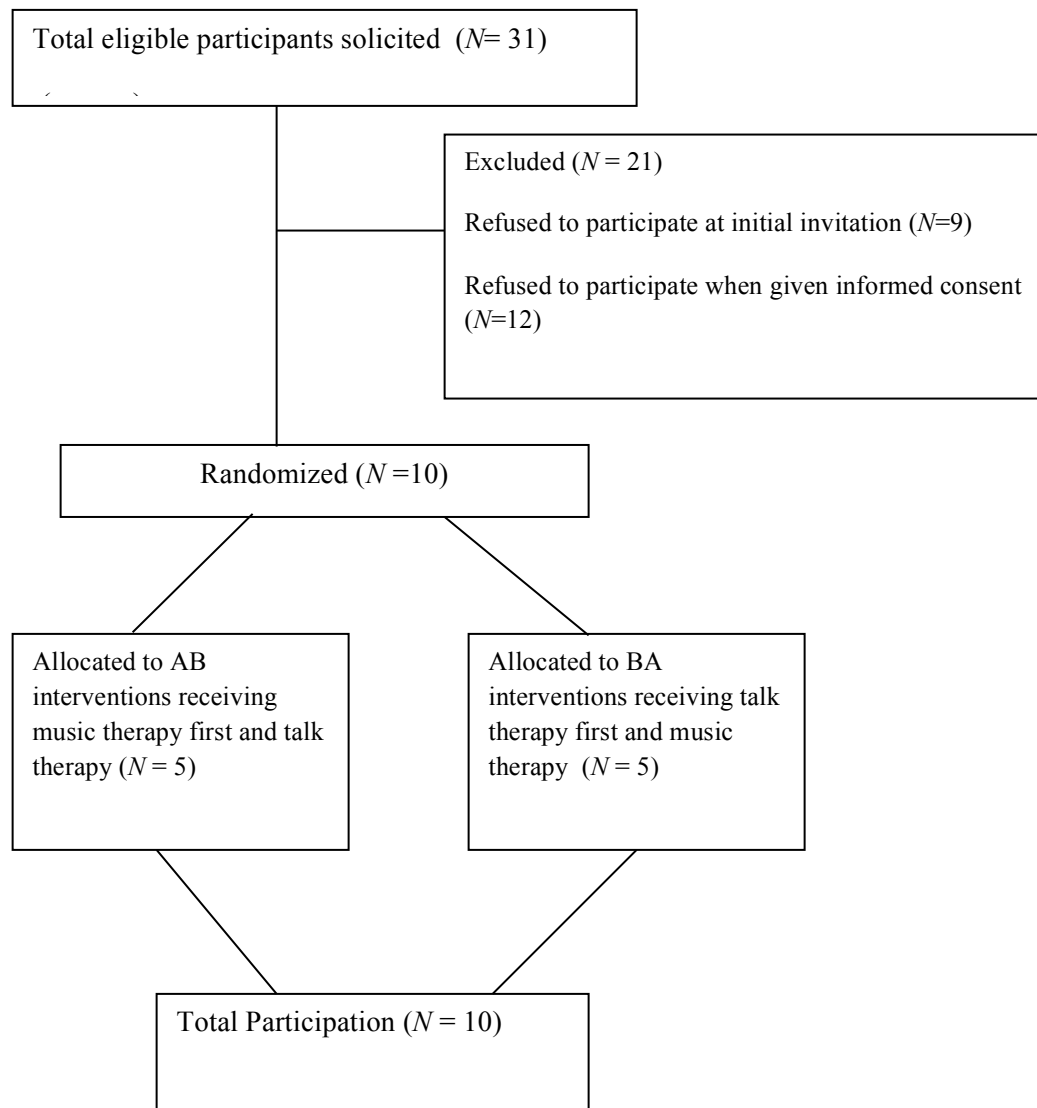
Sessions were video recorded to assure the reliability of the data collected among participants. The consent form for videotaping was provided in a separate space on the consent document with the following information: “이 치료들은 자료 분석을 위해 비디오 촬영으로 진행될 것입니다. 비디오는 연구 목적 이외에 그 어느 누구와도 공유되지 않을 것이며 연구가 끝난 후 폐기 처분 될 것입니다. 귀하는 언제든지 어떤 이유에서든지 비디오 촬영을 중단할 권리가 있으며 원본은 연구자의 잠긴

서류함에 안전하게 보관될 것입니다.” In the English translation: "The researcher is asking for your permission to allow her to videotape as part of this study. The recording will only be used by the researcher and will never be shared or given to anyone. You are free to stop the recording at any time for any reason and have the right to have the recording destroyed. The recording will be stored in a locked office to which only the researcher has access, until the research is complete at which time the recording will be destroyed." At the time of informed consent, the researcher asked participants if they would like to have a copy of the video as a remembrance. The video was given to the participants at a follow-up visit by one of the interventionists several days following participation.

### **Participants**

A total of ten dyads of patients and their family caregiver participated in this study. They were ten patients and ten family caregivers. Thirty-one dyads eligible to participate ( $N=31$ ) in the study were invited by the interventionists. However, a total of twenty-one dyads declined to participate; nine dyads declined at the time of initial invitation by the interventionists, and twelve dyads declined when given the informed consent form by the researcher. Reasons for not participating include: video recording ( $n=12$ ), not in a good mood ( $n=5$ ), wanted to have privacy ( $n=3$ ), and had to return to work ( $n=1$ ). Figure 1 describes the flow of participants through the phases of recruitment.

Figure 1 Consent to Participate Flow Diagram



Patient participants were admitted to hospice general inpatient (GIP) care. GIP was initiated when patients' pain and symptoms could not be feasibly managed in a home setting or other residential setting. This occurred with a sudden change in symptoms, a change in condition after a period of gradual decline, or when continuous care failed to alleviate the problems. The NHPCO (2012) provided common patient statuses that may lead to a change to the level of GIP

care, which are “pain or symptom crisis not managed by changes in treatment in the current setting or that requires frequent medication adjustments and monitoring; intractable nausea/vomiting, advanced open wounds requiring changes in treatment and close monitoring; unmanageable respiratory distress; delirium with behavior issues; sudden decline necessitating intensive nursing intervention; and imminent death – only if skilled nursing needs are present” (p.3).

Due to rapid changes and declining symptoms in patients receiving GIP care, family caregiver participants were the primary source of data collection to evaluate intimacy measures in a family-patient relationship at the end-of-life. The family caregivers consisted of eight females and two males between the ages of 42 to 69 ( $M = 54.1$ ,  $SD = 8.24$ ) years old. The caregivers’ relationships to the patients were: five daughters, two daughters-in-law, one sister, one husband, and one son.

### **Setting**

GIP is intended to be short-term care with similar procedures as an acute care hospital setting, and requires that registered nurses are available 24 hours per day to provide direct patient care (NHPCO, 2012). The study was conducted in a semi-private room at a hospice inpatient unit. The semi-private room used for this study contained two beds, bedside tables, chairs, small TVs, and private closets. One bed was located adjacent to the exterior wall by a window. The other bed was located closer to the entrance of the room. A patient sometimes shared a room with another patient, which resulted in some minimal noise (e.g., moderate ambient sounds coming from a television). However, previous observations by the researcher indicated this noise had minimal distracting effects on the participants. The researcher proceeded with data collection only if the roommate agreed to conduct the study.

## **Interventionists**

In the patient's room, a board-certified music therapist provided a Music Therapy Session (MTS), and a certified chaplain a Talk Therapy Session (TTS). Both sessions were placed approximately two hours apart. The board-certified music therapist had a Bachelors' Degree in music therapy from an American Music Therapy Association approved training program in the U.S. with one year of work experience in hospice settings. The certified chaplain had a Bachelor's Degree in seminary with two years of work experience in hospice settings. The present researcher served as an observer who did not participate in either the MTS or the TTS. The researcher video-recorded each session, and had no control over the interventionist. Both the music therapist and chaplain remained blind to the research questions in order to decrease bias, and the possibility of their assessment being swayed by concerns regarding the study design or the outcome (Gearing, Mian, Barber, & Ickowicz, 2006). The interventionists provided sessions as part of their regular scheduled duties, and did not specifically design the sessions for the purpose of this study.

## **Materials**

Materials used for the Music Therapy Session (MTS) included a Martin LXX2 six-string acoustic guitar with steel strings and a video camera (Sony HDR-CX405). The Talk Therapy Session (TTS) used spiritual objects (e.g., spiritual messages, Bible) provided by a chaplain, and a video camera (Sony HDR-CX405). In each session, a video camera was placed in the opposite corner from the patient adjacent to the wall. The researcher used Adobe Premiere Pro software to make a video for the participants who wanted to have it as a remembrance of their loved one. The copy of the video was provided to the participants several days after following research participation.



## **Study Design**

This study was an exploratory case study to gather information about differences between music therapy and talk therapy. The researcher used an AB/BA crossover design, in which half of the participants were assigned to sequence AB, receiving the Music Therapy Session (MTS) in the first treatment period, and then the Talk Therapy Session (TTS) in the second treatment period schedule (Jones & Kenward, 1989). The other half were assigned to sequence BA, with the treatments reversed. The researcher used the Research Randomizer website ([www.randomizer.org](http://www.randomizer.org)) to randomize treatment sequences. Each participant dyad received music therapy and talk therapy on the same day spread two hours apart.

## **Procedure**

If the patients and families indicated interest in participating in the study, the researcher met with them, provided a description of the study, answered questions, and participants signed the informed consent document. Subsequent to obtaining informed consent by the researcher, participants were assigned to both the Music Therapy Session (MTS) and Talk Therapy Session (TTS) with their loved one for a minimum of 15 minutes. Considering consistency within a dataset, after the interventionist provided a five-minute initial introduction, the researcher recorded the first ten-minute segment of the given session and viewed it later for data analysis. In the first five minutes, the interventionist and researcher introduced self, role, and purpose of the visit, and then the researcher placed a video camera to the opposite corner from the patient.

Each participant dyad received music therapy and talk therapy on the same day approximately two hours apart. The researcher randomly assigned the dyad to the AB, or BA sequence. All sessions took place at the patient bedside where family caregivers were present with their dying loved one. The researcher was present in every session, but served as an

observer who did not participate in either the MTS or the TTS. The board-certified music therapist led the MTS, and the certified chaplain, the TTS. The researcher summarized and included a description of the typical music-based and talk-based interventions used with clients. (See Appendix A).

## **Measurements**

In order to measure the frequency of intimacy, the researcher created the observation tool, Family Intimacy Observation Sheet (FIOS) based on previous research studies (See Appendix B) (Clair & Ebberts, 1997; Hu, Wood, Smith, & Westbrook, 2004; Moss & Schwebel, 1993; Popoola, Adebawale, Akintomide, Olatomide, 2012; Savage, & Taylor, 2013; Tolstedt & Stokes, 1983). The FIOS provides a checklist of observable intimacy behaviors with family caregivers in three domains. The domains include a verbal intimacy, affective intimacy, and physical intimacy (Tolstedt & Stokes, 1983). The FIOS was designed for use by hospice clinicians as an assessment tool to identify strengths and needs of a family-patient relationship at the end-of-life.

The researcher adopted previous research by Savage and Taylor (2013) to develop an appropriate measurement tool for this study. Savage and Taylor found no existing data collection instruments that were suitable for family-patient interactions in hospice settings; therefore, they developed the Caring Behaviors Observation Sheet (CBOS). The most frequently observed caring behaviors of the family members during music therapy included: (a) increased eye focus on the patient, (b) softened facial expression, (c) emotional response of tears, and (d) moving a chair to sit closer to the patient. Analyzing the most frequent caring behaviors of families identified in the CBOS, the current researcher included these behaviors in the FIOS to find the evidence of music therapy in supporting a family-patient interaction. In addition, the CBOS

relied primarily on measuring nonverbal interactions through music activities, which is limited to use by only music therapists. To implement procedures that are practical and suitable for other hospice professionals, the present study excluded musical behaviors such as ‘joining in singing’ that were included in the CBOS, and added both verbal and nonverbal items to assess a range of behaviors in family caregivers of dying patients.

### **Data Collection**

Sessions were video recorded and viewed later to analyze reliable and accurate data among participants. Using a partial interval recording method, the researcher measured family caregivers’ intimacy acts by placing an “X” for occurrence and an “O” for nonoccurrence. Partial interval recording included behavior that occurred in any part of the interval, and that behaviors did not usually consume the entire interval. For example, the researcher marked down an “X” for occurrence when a participant engaged in a behavior multiple times during the interval or only once.

In the FIOS, a ten-minute segment of the session was separated into thirty-second intervals with twenty boxes that were used to record the occurrence of behavior. Once the recording was complete, the researcher watched each video at least three times to count the number of behaviors observed in the three domains of the FIOS. Use of an online interval timer that beeped every 30 seconds alerted the researcher to keep track without having to spend time looking at a timing instrument. Upon completion of measurements, the researcher had a second observer go through the same steps as described above. The second observer was a student with a Master’s Degree in special education. The second observer received training and practice from the researcher on how to observe behavior change under observation guidelines of the FIOS, to

check the occurrence of target behaviors using an interval timer, and to compute overall percentage of agreement between observers with SPSS software.

A statistical measurement of agreement between observers, known as *Inter-Rater Reliability* (IRR), was computed to demonstrate consistency among observational ratings (Hallgren, 2012). Although many researchers use the IRR for interpreting and reporting results, many studies use incorrect statistical procedures and fail to report statistical value of the IRR estimates (Hallgren, 2012). Cohen's (1960) kappa statistic measurement is commonly used for assessing the IRR for nominal variables. Kappa is computed based on the equation:

$$K = \frac{P(a) - P(e)}{1 - P(e)},$$

In the Kappa equation,  $P(a)$  represents the relative observed percentage of agreement among raters, and  $P(e)$  represents the probability of expected agreement due to chance. A hypothetical example to illustrate the derivation of  $P(a)$  and  $P(e)$  is that the researcher proceeds to observe the target behavior of "holding hands," using the second observer as the reliability rater. Out of twenty intervals, ten recorded by the researcher, while the second rater counts seven. The researchers organize scores into diagonal cells (See Table 1). Agreements between the two raters about occurrence and nonoccurrence of behaviors will be placed in two of the diagonal cells, and then disagreements between the raters will be placed on the off-cell diagonal cells.

Table 1

*Agreement Matrix for Nominal Variable*

		Rater A		
		Occurrence (X)	Nonoccurrence (O)	Total
Rater B	Occurrence (X)	7	0	7
	Nonoccurrence (O)	3	10	13
	Total	10	10	20

For the data in Table 1, the  $P(a)$  value is indicated by the sum of the diagonal values divided by the total number of subjects,  $(7+10)/20 = .85$ . To compute the  $P(e)$ , the rater A rated the occurrence of holding hands 10/20 times (0.50), and the rater B rated the occurrence of holding hands 7/20 times (0.35). The probability of obtaining agreement of the occurrence of holding hands if ratings were assigned randomly between raters would be  $0.50 \times 0.35 = 0.175$ , and the probability of obtaining chance agreement about the absence of holding hands would be  $(1-0.50) \times (1-0.35) = 0.325$ . The total probability of any chance agreement, the  $P(e)$  value would be then be  $0.175 + 0.325 = 0.50$ ., and  $\kappa = (0.85 - 0.50)/(1-.50) = 0.70$

Possible values for kappa statistics range from  $-1$  to  $1$ , where  $1$  indicates perfect agreement,  $0$  indicates completely random agreement, and  $-1$  indicates perfect disagreement. Landis and Koch (1977) provide guidelines for interpreting kappa values, with values from  $0.0$  to  $0.2$  as slight agreement,  $0.21$  to  $0.40$  as fair agreement,  $0.41$  to  $0.60$  as moderate agreement,  $0.61$  to  $0.80$  as substantial agreement, and  $0.81$  to  $1.0$  as almost perfect or perfect agreement. However, the use of these qualitative phrasal boundaries is debated, Krippendorff (1980) provides a more conservative measure, suggesting that conclusions should be discounted for variables with values below  $0.67$ , tentative conclusions be made for values between  $0.67$  and

0.80, and definite conclusions be made for values above 0.80. For the evaluation of Kappa values, the present researcher will use the Krippendorff's scale to evaluate the IRR coefficients; approximately 0.80 (80%) or above were expected. Achieving less, the researcher excluded the data, revised observation guidelines, and implemented more precise recording procedures with the second observer. The kappa statistic for a set of ratings was computed with SPSS software.

## Chapter 4

### Results

#### Inter-rater Reliability

Results of inter-rater reliability assessing verbal intimacy, affective intimacy, and physical intimacy represented percentage of agreement between two raters. In the Music Therapy Session (MTS), the value of kappa for verbal intimacy ( $\kappa = .880, p < .001$ ), affective intimacy ( $\kappa = .888, p < .001$ ), and physical intimacy ( $\kappa = .885, p < .001$ ) indicated almost perfect agreement (Krippendorff, 1980). In the Talk Therapy Session (TTS), the value of kappa for verbal intimacy ( $\kappa = .886, p < .001$ ), affective intimacy ( $\kappa = .880, p < .001$ ), and physical intimacy ( $\kappa = .880, p < .001$ ) represented almost perfect agreement. No items in this instrument had a kappa score below .880.

#### Data Analysis

Data from the FIOS instrument were entered into SPSS for quantitative data analysis. Due to a small sample size, the researcher used a nonparametric method, Wilcoxon Signed-Rank Test to assess the magnitude of the change in the FIOS scores between the MTS and the TTS. Similar to the paired samples *t*-test, the Wilcoxon Signed-Rank Test examines whether we can reject the null hypothesis that no significant difference exists between two sets of scores. Using the Wilcoxon test, SPSS calculates the number of positive and negative differences, the *z*-scores, and the associated probability level. Thus, the outcome indicates an analysis of data and the degree of change (Saltzman, Paternoster, Waldo, & Chiricos, 1982). The effect size for this test was calculated using Cohen's (1988) criteria of  $r = .1$  = small effect,  $.3$  = medium effect,  $.5$  = large effect.

## Research Question

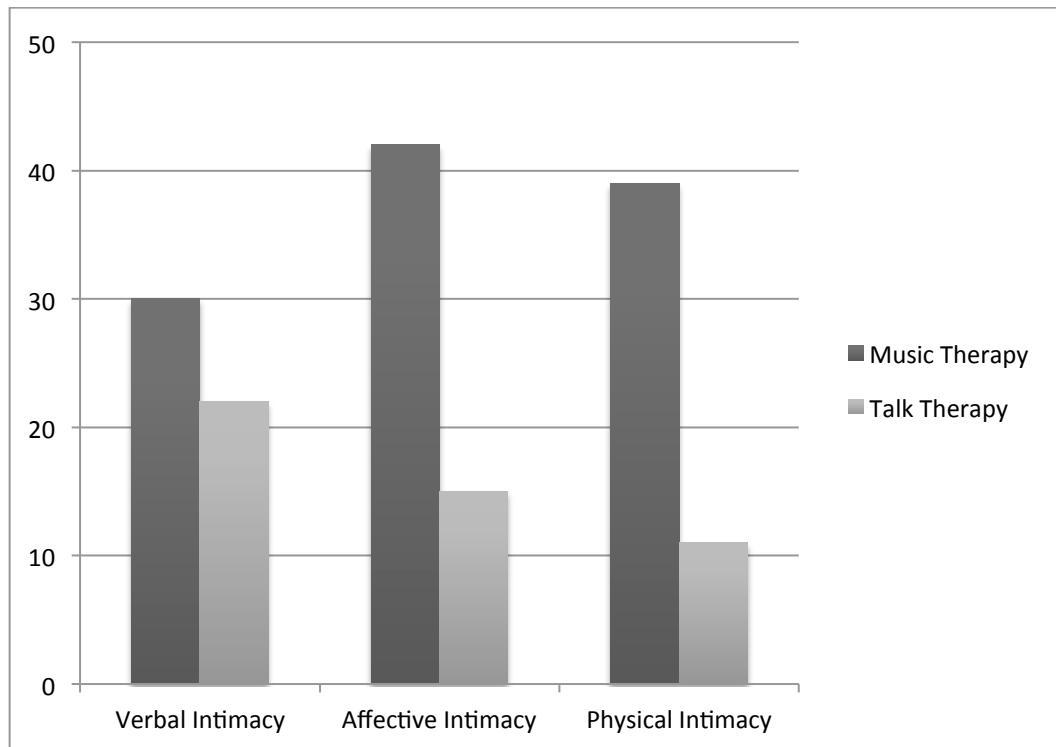
*Is there a difference in frequency of family caregivers' intimacy acts, defined and recorded as verbal intimacy, affective intimacy, and physical intimacy with their dying loved one when comparing music therapy and talk therapy?*

Results from the Wilcoxon Signed-Rank Test indicated that the verbal intimacy between the two treatments (i.e., MTS and TTS) were not found to be statistically significant,  $z = -1.785$ ,  $p = .74$ , indicating music therapy ( $Mdn = 30$ ) was not significantly different in increasing verbal intimacy compared to talk therapy ( $Mdn = 22$ ). Although there was no significant difference in overall verbal intimacy between the two treatments, one specific behavior of “verbally letting go of patient” was significantly different ( $z = -2.413$ ,  $p < .05$ ) with a large effect size ( $r = -.540$ ), indicating music therapy ( $Mdn = 9.5$ ) was significantly different in increasing verbal expression of letting go when compared to talk therapy ( $Mdn = 1.0$ ).

Although there was no significant difference in increasing verbal intimacy, the affective intimacy scores between the MTS and the TTS were significantly different,  $z = -2.803$ ,  $p < .05$  with a large effect size ( $r = -.627$ ). This indicates that music therapy produced a significant increase in physical intimacy compared to talk therapy (MTS  $Mdn = 42$ , and TTS  $Mdn = 15$ ).

In the area of physical intimacy, the MTS and the TTS were significantly different,  $z = -2.805$ ,  $p < .05$  with a large effect size ( $r = -.627$ ), indicating music therapy produced a significant increase in physical intimacy in comparison to talk therapy (MTS  $Mdn = 39$ , and TTS  $Mdn = 11$ ). Figure 1 depicts group median scores of verbal intimacy, affective intimacy, and physical intimacy between music therapy and talk therapy.





*Figure 1.* Treatment median scores on the FIOS between music therapy and talk therapy

## **Chapter 5**

### **Discussion**

Caregiving is often referred to as a dyadic relationship that involves communication of personal feelings and information to another person, but when one member of the dyad develops a serious illness, the relationship shifts from reciprocity to a greater burden on the caregiver (Fauth et. al., 2012). Due to this increased burden, and the highly emotional nature of hospice care, family caregivers of dying patients may be at risk for relational difficulties. Enhancing coping skills through increased meaningful interactions between patient and family can be a vital part of end-of-life care. Thus, this present study explored differences between music therapy and talk therapy on verbal, affective, and physical intimacy in the family-patient relationship at the end-of-life.

#### **Verbal Intimacy**

Although differences in overall verbal intimacy were not statistically significant, both music therapy and talk therapy had a positive impact on verbal intimacy. At the beginning of sessions, both the music therapist and the chaplain demonstrated empathy for the caregivers' current emotions towards a dying loved one. By actively listening to emotional pain and struggles related to caregiving of a dying loved one, the interventionists helped the caregivers become aware of their current feelings. Many family members are unmindful of their own feelings because of the intensity of near-death experiences of their loved one; recognizing these feelings (e.g., anxiety, tiredness) related to caregiving is an initial and important step in the grief process (Parameshwaran. 2015). In addition, the length of a 10-minute observation period in music therapy seemed short to measure the occurrence of verbal communication in the participants. Songs provided by the music therapy interventionist were approximately three to

five minutes to a given session, thus limiting the time allowed for family caregivers to share a conversation with their loved one.

Although the frequency of overall verbal intimacy appeared similar between music therapy and talk therapy regarding emotional expression, the results revealed that the participants in the MTS exhibited a significant increase in verbal expression of letting go of a loved one. Whereas only one family caregiver in the TTS participated in letting go (e.g., saying good bye, giving permission to die), more than half of the caregivers ( $n=6$ ) in the music therapy condition verbalized letting go to their dying loved ones. In music therapy, listening to songs about releasing or saying goodbye seemed to help family caregivers to say and give permission for a loved one to die. In addition, many caregivers used song lyrics to communicate with their dying loved one. For instance, one caregiver requested a song for her husband facing imminent death. The final words of the song were “May God be with you until I see you again.” She said to her husband during music, “I will see you again up in heaven, so it is okay to go there now.” The caregiver thanked the music therapist for visiting, saying that the music helped her say goodbye to her husband in a meaningful manner. Her husband died a few hours later that day.

Lowey (2008) highlighted the importance of letting go in end-of-life care, as it requires a shift in thinking about the acceptance of an impending loss, and the realization of death as a part of natural life. Lowey suggested that letting go could lead to an improvement in the caregiver’s wellbeing by recognizing and accepting major life shifts and changes after the death of a loved one. Therefore, use of music therapy as a stimulus for letting go can serve to promote coping strategies, and improve wellbeing in a difficult situation.

## **Affective Intimacy**

Outcomes of the current study indicated that family caregivers in the MTS experienced a significant increase in affective intimacy towards a dying loved one when compared to the TTS. Affective intimacy refers to sharing of emotions to encourage reconnection, and building of an intimate relationship with one another (Eryilmaz, & Atak, 2009). The present study included caregivers' emotions expressed through nonverbal behaviors (e.g., eye contact, smiles, tears) to discern these behaviors from verbal behaviors listed in the verbal intimacy domain. The caregivers receiving music therapy demonstrated a higher number of affective responses while listening and/or singing songs together, when compared to verbal conversation in the TTS. For example, more than one third of the caregivers who cried during some portion of the music therapy session reported that they were able to approach challenging emotions caused by the loss of a loved one. This positive outcome was possible given a single session of music therapy lasting ten minutes.

Whereas a chaplain only used verbal techniques and active listening for support, a music therapist had the addition of musical stimuli. Such stimuli appeared to result in an increased engagement in the therapeutic process. For instance, the music therapist asked every patient/family what song they would like to hear. If they could not specify a particular song, the therapist then provided two contrasting song options (e.g., energetic or relaxing). The music therapist commented on the importance of giving two options as a form of assessment to see which direction patients/families wanted to go on a particular day. One nonverbal patient was able to nod or shake his head to answer and choose "energetic" when given song options. During music, the patient and a young sister shared smiles and laughter together, and the sister commented that music made the present situation more acceptable and bearable.

Interestingly, this nonverbal form of emotional expression (i.e., affective intimacy) appeared to act as an impetus to initiate verbal and physical intimacy acts in the family caregivers. A number of caregivers who were emotionally aroused by music at the beginning of the session tended to exhibit higher frequency of verbal expression and physical contact with a dying loved one. Although with less frequency, the results in the TTS were consistent with the MTS condition, indicating that higher rates of affective intimacy at early intervals were followed with an increased number of positive verbal and physical behaviors in the family caregivers. This finding is supported by Lowey (2008), in that intimate interactions occur when an individual is emotionally attached to a person who meant something. Recent studies in clinical psychology also highlight the critical role that emotions play in motivating positive behavior change (Baumeister, Vohs, DeWall, & Zhang, 2007; Gutnik, Hakimzada, Yoskowitz, & Patel, 2006). Thus, music-based interventions can increase positive emotional responses in listeners, which may influence the likelihood of engaging in behavior change during a therapeutic process.

### **Physical Intimacy**

Results of physical intimacy data from the current study indicated that family caregivers receiving music therapy experienced significantly higher levels of physical intimacy in comparison to talk therapy. Family caregivers in the MTS spontaneously maintained a closer proximity with a dying loved one, and/or engaged in gentle touch as music continued. Interestingly, a majority of caregivers ( $n=7$ ) spontaneously came closer, and held hands with a loved one without therapist verbal prompts during MTS, while in TTS they (except for one) exhibited the behaviors only when a chaplain prompted, “Let’s pray.” This direct religious cue may have influenced the rates of physical intimacy acts, yet the frequency did not significantly increase in comparison to the MTS. One caregiver specifically commented on how music helped

her feel closer to her dying mother. She commented, “I was distancing myself from my mom to protect myself cause it broke my heart to see her suffer. But the music brightened up the atmosphere, and helped me to move closer to my mom.” This also demonstrates the need for relationship-focused interventions, which can assist in the development of effective coping strategies to prepare for the final chapter of a loved one’s life (Lyons, Winters-Stone, Bennett, & Beer, 2016). Music therapy can provide a supportive environment that encourages family members to regain or maintain closeness with a dying loved one.

Outcomes from this present study indicate music therapy improved intimacy in a family-patient relationship at the end-of-life. Family caregivers coping with terminal illness are often unable to establish or maintain intimacy with a dying loved one due to a shift in the relationship role from family to care recipient (Sanders, Pedro, Bantum, & Galbraith, 2006). Supporting intimacy plays an integral and vital role in psychological wellbeing of family members, and mediates the effects of declining health on relationship quality (WHO, 2006).

### **Clinical Implications**

Music therapy interventions, especially those focused on building or maintaining intimacy, could have a positive effect on caregiving behavior and the family-patient relationship. Improving intimacy, and thus improving psychological wellbeing of family members, could reduce caregiving burden caused by emotional stress (e.g., feelings of being overwhelmed or helpless). This decrease in emotional stress could enhance their caregiving effectiveness by being more emotionally available to their loved one who is dying. Decreased stress would engage family members to be more productive, better able to manage grief, and provide quality care to patients while still sustaining themselves. Music-based interventions could provide family

caregivers with important coping strategies that will allow them to better support their loved ones in hospice care.

The Family Intimacy Observation Sheet (FIOS) used in this study can serve as an observational tool to assess the quality of a family-patient relationship, and identify changes in intimacy that may occur. Behaviors listed in the FIOS can guide hospice clinicians to identify whether desired behaviors of family caregivers towards a loved one are changed over the course of therapy. How the caregiver communicates, responds, feels, and interacts with a dying loved one is important to assess in order to facilitate meaningful interactions between patients and families at the end of-life. Observation methods are a helpful tool to reveal the degree to which behavior changes are manifested in a relationship without relying on self-report or an invasive data collection procedure. Hospice professionals could assess caregivers' current status and decide appropriate next steps in treatment to best support the family based on the results of their observations.

Additionally, music therapy may enhance the assessment process by obtaining valuable information about a family-patient relationship at the end-of-life. Music therapy may provide an outlet for emotions that are too painful or confusing to be expressed in other ways (Pavlicevic, 1997). These musical interactions can aid connections and communications through shared verbal language, as well as multi-sensory gestures (e.g., touch, movement, sound, facial expressions) (Stern, 2003). By responding musically, family caregivers may express their complex feelings more readily than words. Thus, the music therapy assessment process may provide valuable information about verbal and nonverbal interactions that can shape the quality of intimacy in a family-patient relationship at the end-of-life.

Looking beyond the hospice setting, music is a therapeutic modality that families can use among themselves to promote intimacy among loved ones. This interaction is not limited to the music therapy setting; caregiver could use a cell phone or tablet anywhere and at anytime to play music that is important to the family. A music therapist could provide instruction to caregivers on supporting their loved one through music, or make a music recording containing patients' favorite music so the family can share music together with their loved one outside the therapeutic setting. This may help the family to connect positively to their dying loved one, effectively reducing the stress and burden of caregiving.

### **Limitations and Delimitations**

**Limitations.** One limitation of the study was the lack of control over the interventions by the researcher. The researcher served as an observer while the music therapist and chaplain provided their normal services at the hospice. Therefore, the researcher was unable to plan treatment or influence therapeutic outcomes during the research process. Neither the TTS nor the MTS were specifically designed to enhance the quality of a family-patient relationship. Thus, the outcomes of this study may not be as strong as with experimental designs in which the interventions are designed specifically to enhance intimacy between family members and their dying loved one. However, the significant differences in affective and physical intimacy between music therapy and talk therapy as a result of common clinical practice may allow for generalization to other hospice settings.

Another limitation of the study was the small sample size. The researcher found it difficult to recruit participants in a hospice setting. The most common reason given for not participating was the video recording of the sessions. Many caregivers reported that recording would be too intrusive for patients approaching death. This concept is supported by the outcomes



of Bain and MacKay (1995), in which the majority of patients felt pressured to consent to video recording, or felt uncomfortable or hesitant to disclose to providers. This may have deterred people from participating in the present study. However, providing a copy of the video at a follow-up visit by the interventionists seemed appealing for the participants. Many appeared to understand that this study was not only for research, but also to support their needs.

**Delimitations.** The single 15-minute therapy session data collection period seemed too short to allow for in-depth conversation between family members and loved ones. Participants appeared to engage more in verbal intimacy as therapy progressed longer than the pre-determined observation time (i.e., 15 minutes). Although data from participants were collected within a 15-minute segment for consistency, the length of each session varied depending on the needs of patients and families; some sessions lasted an hour, others ended in fifteen minutes. Gates (2001) stated that hospice patients are often too weak to participate in a long duration of treatment, and sessions are often divided into a series of segmented portions. Music-based interventions in hospice care may naturally provide this segmented session structure through the use of several songs interspersed with verbal processing and discussion.

Another delimitation of the study was lack of ethnic diversity of participants. The findings may differentiate from studies involving other ethnicities. Interestingly, neither kissing nor hugging behaviors were displayed in either the MTS or TTS, whereas caregivers from New Zealand in Savage and Taylor (2013)'s study exhibited hugs and kisses in music therapy sessions. The results from the current study may reflect the cultural norms and beliefs held by the South Korean population regarding physical contact. Kim (2010) stated Korean adults have a tendency to avoid physical contact in public, indicating that touching upper body parts, such as hands, arms, and shoulders are considered socially acceptable in public, while kisses or hugs are not.

This may differ with other cultures that embrace kissing or hugging as an important form of social greeting and caring behaviors. Due to these cultural differences regarding the role of touch and physical contact, as well as other cultural differences, the findings of the current study may not be generalized to participants from other cultures.

### **Future Recommendations**

The results of this study suggested that an experimental design in which researchers can focus the intervention directly on improving intimacy may maximize the impact of music therapy on therapeutic outcomes. Whereas the current study examined differences between two typical clinical treatments provided in the course of normal music therapy and chaplain services, future studies with carefully controlled conditions can further support the effectiveness of music therapy in the field of hospice care. Music-based interventions could be expanded by carefully structuring therapeutic interventions including transitions, pacing, and intensity to improve family-patient interactions. For example, a music-listening intervention may begin with songs that are important to patients and families in order to increase engagement in the therapeutic process. Use of probing questions, such as how the caregivers perceive and define meaning of a loved one's death and dying could help them acknowledge strengths and challenges in their relationship. Providing active music methods either in the form of singing or playing instruments may help caregivers to express emotions in a supportive and nonthreatening environment. Closing the session with a song associated with the content of discussions could further support caregivers' overall feelings and thoughts about themselves and their loved one.

Replication of this study with a larger sample would determine if the results from the present study could apply to family caregivers on a broader scale. However, music therapy researchers working with hospice populations may find it difficult to conduct large-scale

quantitative studies due to hospice patients' levels of pain and vulnerability. The single case design used in the current study can be expanded in future research studies by utilizing an ABAB design (reversal and withdrawal design) to strengthen the empirical evidence of music therapy effectiveness, in case fewer participants are anticipated.

The author also recommends expanding this study to a more diverse population by transferring these protocols to participants from different cultures. It would be interesting to compare the current findings to future studies with other cultural groups to investigate if there are differences in patterns within family-patient interactions. Findings may be useful for cross-cultural clinicians who work in multicultural environments to successfully support cultural needs of patients and families.

In summary, the differences in intimacy between music therapy and talk therapy demonstrates the positive influence of music therapy on interaction responses between family caregivers and dying patients, although this supposition needs further exploration. As family caregivers of hospice patients are often exposed to emotional and relational stressors caused by the impending separation from a loved one, increasing intimacy in the patient-family relationship may help caregivers cope with this difficult situation. Thus, access to music therapy services can be a positive coping mechanism for family caregivers to effectively manage their stress and emotional exhaustion, enhance well-being, and experience meaningful moments with a loved one at the end-of-life.

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## Appendix A

### Session Summaries

#### List of interventions received by each participant

Participant #	Music-based Interventions Received	Talk-based Interventions Received
1	Music Listening Music-based life review/reminisce	Counseling Prayer
2	Music Listening Music-based life review/reminisce	Counseling
3	Music-assisted relaxation Music Listening	Counseling Prayer
4	Music-assisted relaxation Music Listening	Counseling Prayer
5	Music Listening Music-assisted relaxation	Counseling Prayer
6	Music-assisted relaxation Music-based life review/reminisce	Counseling
7	Music Listening Music-based life review/reminisce	Counseling Prayer
8	Music Listening Music-assisted relaxation	Counseling Prayer
9	Music Listening Music-based life review/reminisce	Counseling
10	Music-assisted relaxation Music-based life review/reminisce	Counseling

## Summary of Music-based Interventions

**Setting:** Inpatient unit with a two-bed room arrangement  
**Population:** Patients with terminal illness & their families

**Interventionist:** A board-certified music therapist (MT)  
**Delivery Schedule:** A 15-minute session delivered to a patient-family dyad

### List of Interventions:

1. Music-assisted relaxation
2. Music Listening
3. Music-based life review/reminisce

<b>Therapeutic Technique &amp; Intent:</b>	<b>Music-based Intervention I Music-Assisted Relaxation</b>
<b>Goal</b>	To reduce pain level
<b>Therapeutic Function of Music:</b>	The patient is guided into relaxation by listening to music improvisation provided by the therapist. Use of V-I chord progression with arpeggio patterns maintains consistency of rhythm during music. Use of steady beats provides a timing cue to facilitate steady breathing patterns. Use of faster/upbeat tempo (60-80bpm) enables patients to perceive energy arousal at the beginning. Then, the gradual decrease in tempo (30-60bpm) acts as a catalyst to ease muscle tension and promote relaxation. The use of relaxing music at the end facilitates a positive emotional outlook such as safe, peaceful or restful.
<b>Music Delivery Method</b>	Live music (Interventionist only)
<b>Person Selecting Music</b>	Pre-selected by interventionist
<b>Intervention Materials</b>	Acoustic guitar (Martin LXX2) & Video camera (Sony HDR-CX405)
<b>Procedures of Therapist Effectiveness:</b>	<ol style="list-style-type: none"> <li>1. The Music Therapist (MT) will sit next to pt and ask pt to rate pain level on a scale of 1 to 10.</li> <li>2. The MT will start the V-I chord progression with loud volume and fast tempo that matches pt's current mood and breathing patterns.</li> <li>2. After a few measures, the MT will encourage pt to breathe deeply. Using 4/4 rhythmic patterns along with V-I chord progression, she will ask pt to inhale, hold the breath, and then exhale slowly.</li> <li>3. When the pt. feels comfortable in breathing, the MT will gradually slow the music and change from 4/4 to 3/4.</li> <li>4. The MT will repeat the step #2; plus encourage the pt. to relax and let go of all tension on each exhalation.</li> <li>5. Vocal improvisation using oo vowels can be added over the chord progression to provide solid melodic and harmonic foundation.</li> <li>6. Upon completion, the MT will ask pt, if current pain level has been changed after the relaxation process.</li> </ol>

<b>Therapeutic Technique &amp; Intent:</b>	<b>Music-based Intervention II Music Listening</b>
<b>Goal</b>	To increase comfort level
<b>Therapeutic Function of Music:</b>	The primary modality is listening. The patient will be guided into music listening by listening to live sounds provided by the therapist. Song selection based on the patient's age, religion and culture promotes levels of interest and engagement during the music- listening intervention. Use of chord progressions and modulation between songs provides smooth music transitions and therefore creates a safe and supportive environment in which the patient/family can receive comfort and support. Gradual decrease in tempo and dynamics towards the end serves as a stimulus to increase relaxation and comfort.
<b>Music Delivery Method</b>	Live music (Interventionist only)
<b>Person Selecting Music</b>	Participant selected from limited set
<b>Intervention Materials</b>	Acoustic guitar (Martin LXX2) & Video camera (Sony HDR-CX405)
<b>Procedures of Therapist Effectiveness:</b>	<ol style="list-style-type: none"> <li>1. The MT will sit on a chair next to pt/family, and ask "How are you feeling today?"</li> <li>2. The MT will say, "What would you like to hear today?"</li> <li>3. If pt/family cannot specify their preferred song, the MT will give two contrasting options (e.g., fast versus slow) to assess which direction pt/family are wanting to go on a particular day.</li> <li>4. After completion of the first song, the MT will play V-I chord progression to maintain a supportive environment musically, and ask, "Is there another song you would like to hear?"</li> <li>5. Towards the end of the music set, the MT will gradually soften and slow the music to promote relaxation and comfort.</li> <li>6. Upon completion, the MT will ask pt/family, if there are any changes before and after the music listening.</li> </ol>

<b>Therapeutic Technique &amp; Intent:</b>	<b>Music-based Intervention III</b> <b>Music-based life review/reminiscence</b>
<b>Goal</b>	To improve life review/reminiscence
<b>Therapeutic Function of Music:</b>	During the life review process, use of familiar music regarding the patient's age, culture, and religion serves as a stimulus to evoke memories and feelings of past events. Different genres of 1940's and 1950's music are available to ensure familiarity and participation. Providing a wide range of music genres from Country to Religious facilitates integration of cultural, religious, spiritual and personal components of lifetime. The quality of sound provided by the therapist is bright, yet soft in resonance to provide comfort and a calm environment for the patient at life's end. Use of guitar in various accompaniment styles (i.e. arpeggio, strumming, finger-picking patterns etc.) promotes musical interests as well as provides dynamic features in music.
<b>Music Delivery Method</b>	Live music (Interventionist only)
<b>Person Selecting Music</b>	Participant selected from limited set
<b>Intervention Materials</b>	Acoustic guitar (Martin LXX2) & Video camera (Sony HDR-CX405)
<b>Procedures of Therapist Effectiveness:</b>	<ol style="list-style-type: none"> <li>1. The MT will sit on a chair next to pt/family, and ask "How are you feeling today?"</li> <li>2. The MT will say, "What would you like to hear today?"</li> <li>3. If pt/family cannot specify their preferred song, the MT will give two contrasting options (e.g., fast versus slow) to assess which direction pt/family are wanting to go on a particular day.</li> <li>4. The MT will begin to sing the song chosen by pt/family.</li> <li>5. After the last verse, the MT will ask, "What made you choose this song?" The MT will prompt pt/family to share memories associated with the song. The questions include the following: "When did you first hear it?" "What was your life like when this song was popular?" "What does this music remind you of?"</li> <li>6. The MT will actively listen and validate their feelings and thoughts.</li> <li>7. The MT will ask, "Is there any other song that you would like to hear?"</li> <li>8. Steps 3-7 will be repeated until pt/family ends the session or meets the goal.</li> </ol>

## Summary of Talk-based Interventions

<b>Setting:</b>	Inpatient unit with a two-bed room arrangement	<b>Interventionist:</b>	A certified chaplain (CH)
<b>Population:</b>	Patients with terminal illness & their families	<b>Delivery Schedule:</b>	A 15-minute session delivered to a patient-family dyad

**List of Interventions:**

1. Counseling
2. Prayer

<b>Therapeutic Technique &amp; Intent:</b>	<b>Talked-based Intervention I Counseling</b>
<b>Goal</b>	To improve verbal expression
<b>Therapeutic Function of Counseling:</b>	There are three core counseling skills: empathetic listening, reassurance and reflection (Chen & Gibling, 2002). Providing empathetic listening may promote the participants' feelings of acceptance and belonging. This may provide a safe environment in which patients and family caregivers can express their thoughts and feelings regarding the impending death. While empathetic presence helps them feel heard, reassurance allows for patients and caregivers to find ways to accept and cope with the reality of death. Providing education about the dying process while acknowledging emotional needs may help the participants gain sources of strength and comfort. The chaplain will assist patients and caregivers in finding a sense of meaning and hope in life by encouraging them to share memories, and feelings about grief and the nature of death.
<b>Intervention Materials</b>	N/A
<b>Procedures of Therapist Effectiveness:</b>	<ol style="list-style-type: none"> <li>1. The CH will sit on a chair next to pt/family, and ask "How are you feeling today?"</li> <li>2. The CH will encourage them to express their feelings and thoughts, asking "Are there any concerns you have about yourself or your loved one?"</li> <li>3. The CH will actively listen and use probing questions to help them recognize important feelings and information. The questions include: Who or what provides the patient/family with strength and hope? What does dying mean to you? What helps the patient/family get through this end-of-life experience?"</li> <li>4. The CH will validate and normalize what the pt/family going through, and help them confront end-of-life experiences.</li> <li>5. The CH will close the session, saying "May peace be with you."</li> </ol>



<b>Therapeutic Technique &amp; Intent:</b>	<b>Talked-based Intervention II Prayer</b>
<b>Goal</b>	To improve spiritual comfort
<b>Therapeutic Function of Music:</b>	Prayer can be a spiritual coping mechanism to deal with suffering and an access channel to God/higher power. Prayers may evoke spiritual conflicts or concerns resulting from death and dying. Prayers based on scriptures from the Bible or spiritual passages may reassure patients and caregivers about their relationship and connectedness with themselves, with one another, and with the sacred (Esperandio, & Ladd, 2015). By acknowledging and respecting the participants' religious backgrounds and rituals, the chaplain will offer prayer in a manner that is compatible with their personal belief, values, and comfort level. The chaplain will be an empathetic listener and involve the participants' concerns into prayer to help them feel understood and supported.
<b>Intervention Materials</b>	Bible
<b>Procedures of Therapist Effectiveness:</b>	<ol style="list-style-type: none"> <li>1. The CH will sit on a chair next to pt/family, and ask "How are you feeling today?"</li> <li>2. The CH will encourage the pt/family to express their feelings and thoughts, asking "Are there any spiritual concerns you have about yourself or your loved one?"</li> <li>3. The CH will actively listen and share spiritual passages to validate what the pt/family have shared. Example of spiritual passages include:</li> <li>4. The CH will summarize what the pt/family shared in their discussion and lead the pt/family into prayer, saying "Let's pray."</li> <li>5. The CH will close the session, saying "May God give you peace and comfort."</li> </ol>

## Appendix B

### FIOS – Family Interaction Observation Sheet

#### Verbal Intimacy

Name: \_\_\_\_\_ Observation Date: \_\_\_\_\_ Session Type: ☐ MTS ☐ TTS

Gender: \_\_\_\_\_ Relationship: \_\_\_\_\_ Ethnicity: \_\_\_\_\_

<b>Verbal Intimacy</b> Self-disclosure – whether to reveal one’s thoughts, feelings, or past experiences with patients.																						
#	Family Caregiver...	Observation Guidelines	Observation Number (Place ‘X’ for occurrence. ‘O’ for nonoccurrence)																			
			1	2	3	4	5	6	7	8	9	1	2	3	4	5	6	7	8	9	1	2
			Total /20																			
1	Verbally expressing emotions	Uses words or phrases that describe emotions such as sadness, happiness, guilt, or anger.																				
2	Verbally expressing regrets	Expresses regret regarding past or current experiences																				
3	Engaging in reminiscence/life review	Recalls shared life events, and/or finds meaning in life.																				
4	Verbally letting go of patient	Gives patient permission to say goodbye and pass away.																				
5	Verbally comforting patient	Gives patient permission to say goodbye and pass away.																				

## Affective Intimacy

Name: \_\_\_\_\_ Observation Date: \_\_\_\_\_ Session Type: ☐ MTS ☐ TTS

Gender: \_\_\_\_\_ Relationship: \_\_\_\_\_ Ethnicity: \_\_\_\_\_

Affective Intimacy	
Nonverbal expression of affections and emotional bonding with patients by using gestures or facial expressions.	
#	Family Caregiver...
#	Observation Guidelines
Observation Number (Place 'X' for occurrence, 'O' for nonoccurrence)	
Total /20	1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
1	Increased eye focus on patient Maintains eye contact with patients for more than three seconds.
2	Expressing emotions through tears Expresses emotions through weeping, perhaps accompanied by sobs or moans.
3	Smiles and/or laughter Curves up lips and/or expose teeth to smile and laugh while looking directly into the eyes of patient.
4	Softened facial expression Changes from eyes squint or frowns in forehead to relaxed eyes or brows as therapy continues. It does not count in each interval if FC's eyes and facial muscles are not tensed for duration of visit

## Physical Intimacy

Name: \_\_\_\_\_

Observation Date: \_\_\_\_\_

Session Type: ☐ MTS ☐ TTS

Gender: \_\_\_\_\_  
Relationship: \_\_\_\_\_  
Ethnicity: \_\_\_\_\_

# Physical Intimacy

Physical expression of affection towards patients by gently touching or physically being close.

[illegible]